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ABSTRACT

The paper examines the role of the recreation therapist in the new trend towards home care for the ventilator assisted individual. The focus on home care necessitates that the recreation therapist familiarize parents with the rationale for activities as well as providing them with information about a variety of future leisure pursuits. In addition, emphasis should be placed on providing children with opportunities for control over their environment through adapted recreational equipment. Additional concerns of community reintegration and safety should be explored to promote successful leisure functioning within the home environment. (CL)

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# Recreation Therapy: Implications for the Ventilator Assisted Child

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With a new trend towards home care for the ventilator assisted individual, Recreation threapists must begin to look at new avenues of treatment. No longer is a single-faceted program of developmental stimulation sufficient, but rather a multi-faceted program that encompasses parental education, adapted equipment, and community reintegration. Methods and rationale behind such an all-encompassing program are discussed.

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The need for ventilator assistance, for all or part of a daily routine, is a reality known to an increasing number of children. Whether it be due to an accident, neuromuscular disease, or birth-associated problem, chronic ventilator assistance is a common phenomenon in many hospitals.

Traditionally, children requiring the technological assistance of a ventilator have faced long-term placement in a medical institution. Consequently, Recreation Therapy goals were oriented toward the developmental stimulation and emotional support necessary to sustain a chronically ill child in that environment. However, many of the children are not medically unstable, and therefore, do not require continuous medical intervention. With this thought in mind, several programs throughout the United States have been developed to facilitate home care for the ventilator-assisted individual (VAI). The program at Children's Hospital has an overall philosophy of care that is "dedicated to the facilitation of the development of the best possible quality of life for these individuals."[1] For this home care philosophy to be feasible, the hospital personnel must work together in a cooperative effort. This team-approach is a very complex endeavor and requires input and support by all persons involved with the child.

Along with this new focus on home care for the VAI, comes a new focus for the Recreation Therapist. Now, recreation therapy must address the additional needs of parent education, adaptive devices for leisure activities, and, most importantly, the need for community reintegration of the ventilator assisted child. These three areas are vital stepping stones to the overall goal of home placement. With such a comprehensive therapy plan, going home can be a successful experience for everyone involved.

## PARENT EDUCATION

As the treatment team begins to prepare the VAI for discharge, they must also prepare the parents or guardians for long-term home care. The parents will become the child's initial source of recreational activity. One cannot assume this will be an automatic awareness or orientation on their parts, as the amount of other responsibilities they carry home is enormous. Therefore, it is imperative to carefully educate the parents on the necessity, rationale and methods behind every activity or idea presented.

In addition, a variety of activities should be suggested for the child as he/she grows older. At times this is easily done, as for a child who appears "normal", with the exception of the ventilator. Whereas, parents

may find it difficult to be innovative in providing recreational opportunities for children experiencing accompanying conditions such as quadraplegia. The Recreation Therapist should be a source of ideas for present as well as future participation in recreational activities.

Ideally, children will help direct their parents toward leisure activities they wish to pursue. In most instances a combined effort between the parent and child will be necessary for successful leisure participation.

Including the parents in all aspects of the recreation therapy plan will ensure their understanding and ability to provide their child with the opportunity for a healthy leisure lifestyle in the familiar surroundings of their home community. Only if this is accomplished will the goals set by the Recreation Therapist be attained.

## ADAPTED EQUIPMENT

A primary concern regarding these children is a need for some type of control over their environment. Often times, the outlet they use to control others will center around feeding problems (i. e., food refusal) or other behavior problems, such as disconnecting the ventilator tubing. If they are given a variety of alternatives, the negative behaviors usually decrease. The use of

adapted recreational equipment is an excellent opportunity to provide them with such control.

Almost all ventilator-assisted persons will require some type of adaptation for normal leisure functioning. The amount of adaptation will depend on the extent of accompanying disabilities. An ambulatory child with a solitary diagnosis requiring ventilator assistance may only need the simple adaptation of increasing the length of the ventilator tubing. (The ventilator setting must be adjusted by a qualified person to accomodate this change.)

On the other hand, an individual with an associated diagnosis of quadraplegia will necessitate an assortment of adaptive devices. Clarence, a 19 year old patient who has quadraplegia due to a diving accident, uses an adapted mouthstick which allows him to paint, draw, write letters, type, and turn pages.
This particular type of mouthstick is made using a "gooseneck" tubing which has special implications for the VIA, in that it does not require a large amount of neck flexion, and can be positioned around the ventilator hose.

Jacob, a 2½ year old child who also is a VAI with quadraplegia uses several devices which allowed him some control over his environment. A tape player was easily

rerouted through a switch which he could operate using his chin. A small easel was mounted on a board which allowed him to read along with the tape.
In addition, a variety of battery-operated toys, such as cars and trains were also altered to allow independent operation.

Many teenagers requiring the use of a ventilator due to a traumatic injury had accidents while participating in recreational pastimes. They are not used to a sedentary lifestyle and often find it humiliating to have to rely on others for very simple tasks such as turning on the stereo, television, lights, call switch, etc. Devices which allow independent control of these activities can be obtained from a local electronics store.

"A good program needs to be creative, flexible and adapted to specific needs of the individual."[2] The ventilator-assisted patient is especially vulnerable to this need. With a bit of imagination, adapted toys and equipment can be fabricated to elicit the patient's active participation and control over part of the environment.

## COMMUNITY REINTEGRATION

The Recreation Therapist must acknowledge the need for community reintegration of the ventilaotr-assisted

patient. Impairment in mobility is a problem encountered to some degree by all of these children and an area of utmost concern. Because of mobility limitations imposed by the ventilator itself, it is not uncommon for these children to stay in one place throughout most of the day, resulting in decreased social interaction skills. However, with a new emphasis on going home, it is necessary to educate the parent and child to the new possibilities for leisure activities and daily routines within the community.

The first step which must be taken to implement this need, is to determine the modifications necessary for the patient to participate. Some children will need no adaptations at all, if they are allowed time off the ventilator during their daily routine. On the other hand, children requiring continuous ventilation can participate in excursions in the community in one of two ways. First, a child can be temporarily ventilated by use of an ambu bag or other mechanical ventilation. However, this method is very tiresome to the parent or therapist and can make mobilizing the wheelchair difficult.

Second, the child's wheelchair can be adapted to carry a portable ventilator in a variety of ways.

If the child is a toddler or smaller and does not require a wheelchair, a cart can be used

to hold the child, ventilator, and other necessary equipment.

It is a very important concept that all children are in need of normal, everyday activities. These include going to the grocery, library, family reunions, to the park or zoo, and going to school. It is with these types of activities that children learn about the world they live in. The fact that a child relies on ventilatory assistance should not exclude him from these activities.

The use of a strong community reintegration program can help both the parents and the child. If the parents are shown that the child is not restricted to the house and does not necessarily cause a major change in their lifestyle, then the child and the ventilator can be more easily accepted. It is important to send the family home with as normal a routine as possible. The parents should be included in several community fieldtrips in order to educate them on the steps necessary for successful reintegration. If the parents feel comfortable taking their child into the community, the child will more readily accept social experiences.

For the child, a community reintegration program can provide more than just fun. It can provide an avenue for compensating for limitations in areas such as social

interaction skills, wheelchair mobility, acceptance by society, leisure functioning skills, and much more. It is not unusual for the VAI to too easily accept the idea of non-participation. It is up to the Recreation Therapist to provide them the opportunity to once again experience success in leisure settings. According to McDaniels (1971), participation in social activities will frequently result in greater acceptance by non handicapped peers, thus resulting in an increased self-concept. Because active leisure participation is in direct positive correlation to the level of self-concept, it seems essential to foster participation for the ventilator-assisted child. Then, with a feeling of well-being and an increased self-concept, the child should begin to seek out positive social interactions on his/her own initiative.

## SAFETY

When planning such a complex therapy program for the VAI, safety should always be a consideration. It is easy to get bogged down with all the issues accompanying treatment of a child requiring technological assistance, but, with proper planning and preparation, many of the risks involved will be alleviated.

Prior to beginning community outings the treatment team should develop protocol for including the VAI in

this program. If the child is dependent upon the ventilator during the outing, a doctor or respiratory therapist should accompany him/her. Arrangements for suctioning the tracheostomy should be made. This can be done by anyone who has been trained in the procedure by a registered respiratory therapist.

A supply kit should always accompany the VAI on any excursions outside the hospital. This kit should contain those items necessary for proper tracheostomy care (i. e. portable suction machine, suction catheters, ambu bag, spare tracheostomy tube, normal saline ampules). Also included in this kit should be protocol for emergencies, including phone numbers for doctors, hospitals, ambulance service, and respiratory therapists.

Weather can have an effect on the ventilator, and should be considered carefully before going outside. The ventilator should not be exposed to rain or snow unless it is protected with a plastic coating as it may become electrically dangerous (do not cover the air inlet filter of the ventilator). Extremes in heat or cold can effect the high and low pressure settings. These can be adjusted with a screwdriver by a qualified respiratory therapist.

With proper procedures developed prior to involving the VAI in a community reintegration program, safety will

not be a difficult goal to attain. Having basic supplies, a good understanding of procedures, and support from the treatment team will ensure a positive and beneficial outing.

## SUMMARY

Home care for the ventilator-assisted child is a new concept; however, it is a phenomenon which is spreading rapidly. Therefore, the recreational providers of health care facilities must begin focusing on the skills needed for successful leisure functioning within the home and community environment.

The emphasis of the hsopital recreation program for these children must undergo alteration if it is to meet the needs of home placement. The areas of parental education, adapted equipment and community reintegration must be intertwined to provide a comprehensive approach to a healthy leisure lifestyle. Just as with all persons, recreation activities for the Ventilator-Assisted Individual "provide the stimulation needed to maintain an active interest in one's surrounding, in one's health, in social relationships, and in work and life; such interest, in turn supports other maintenance, health and rehabilitation services, education and therapies."[3]

FOOTNOTES

[1]"Interagency Home Care Program for Ventilator Dependent Individuals," p. 19.

[2]More Homemade Battery Devices for Severely Handicapped Children with Suggested Activities, p. 1

[3]Social Skills Training: A Three Pronged Approach, p. 18

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